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Published in:
European Journal of Cardiovascular Nursing

DOI:
[10.1016/j.ejcnurse.2007.02.005](https://doi.org/10.1016/j.ejcnurse.2007.02.005)

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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2008

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Luttik, M. L., Jaarsma, T., Tijssen, J. G. P., van Veldhuisen, D. J., & Sanderman, R. (2008). The objective burden in partners of heart failure patients; development and initial validation of the Dutch objective burden inventory. *European Journal of Cardiovascular Nursing*, 7(1), 3-9.
<https://doi.org/10.1016/j.ejcnurse.2007.02.005>

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The objective burden in partners of heart failure patients; development and initial validation of the Dutch objective burden inventory

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Received 20 July 2006; received in revised form 17 February 2007; accepted 22 February 2007

Available online 1 May 2007

Abstract

Background: Measures on objective caregiver burden in partners of Heart Failure patients are hardly available and never include HF specific aspects.

Aim: The main objective of our study was to develop an inventory that assesses the objective caregiver burden of partners of HF patients, including the full range of potential care giving demands.

Methods: To develop the inventory, six domains of caregiving demands were identified. Items for the domains were generated from the literature, expert opinion and existing scales. The original 50-items self-report inventory was administered to 321 partners of HF patients. Demographic data of HF partners were collected by questionnaire. Clinical data of the HF patients were collected by chart review.

Results: Component analysis led to exclusion of 12 original items and to a meaningful four-factor solution with a total explained variance of 43%. The components reflected four different kinds of care giving tasks; personal care, emotional, motivational and practical (treatment related) support. They demonstrated good internal consistency and initial validity was supported by a pattern of meaningful associations with external variables.

Conclusion: The Objective Burden Inventory is a promising inventory to assess objective care giving tasks performed by HF partners, including emotional and motivational support. It provides information on the caregiver situation that may help to develop effective interventions.

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Keywords: Caregivers; Partners; Heart failure; Objective burden; Caregiving tasks; Inventory

1. Introduction

Within our current health care system the care for patients with Heart Failure (HF) for the most part takes place within the patient's home and with the help of partners and families. Research has made it clear that the support of a partner is essential in managing the disease [1]. There is also evidence that the support of a partner has positive impact on outcome measures in cardiac patients in general [2] and in patients

with HF [3–5]. Nevertheless, very little attention has been given to the role and position of these partners, let alone the consequences of the disease on their lives [6]. Only a few studies are known in this research area and these studies indicate that partners experience higher levels of psychosocial distress and lower well-being compared to the general population [7–9]. They even may be at risk for physical and mental morbidity and eventually for earlier death [10]. Caregiver burden as an outcome measure has been studied only twice in partners of HF patients [11,12].

In analysing the caregiver situation a distinction is made between objective and subjective burden [13,14]. This

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distinction aims to separate events and activities from feelings and emotions. Objective burden refers to the concrete activities and tasks that caregivers perform resulting from the care giving process. Subjective burden refers to the caregiver's appraisal of the care giving situation and the extent to which the caregiver perceives the situation as burdensome [14]. Both aspects of burden are relevant and it is important to distinguish since objective and subjective burden seemed to be only moderately correlated. Therefore the same levels of objective burden may result in different levels of subjective burden [14]. Interventions to relieve objective burden may need to be different from interventions that relieve subjective burden. Understanding these relationships is important for the development of effective supportive interventions in the future.

Subjective feelings of burden can be measured by a variety of instruments that are designed to assess the concept of perceived caregiver burden in caregivers of chronically ill, such as there are the Caregiver Strain Index [15] or the Caregiver Reaction Assessment Scale (CRA) [16].

Instruments that focus explicitly on the objective caregiver burden are scarce. Despite the relevance of both objective and subjective components of burden both aspects are not well separated and the measurement of caregiver burden often contains both. Generally, objective caregiver burden is measured by a random set of questions that reflect a certain set of tasks. There is no consistency in the kind of tasks that are assessed and emotional support is seldom defined as a specific type of care giving task [17].

HF is a serious, life-threatening condition with serious consequences in daily life. The course of the disease is characterized by debilitating physical symptoms, frequent hospitalizations and poor prognosis [18]. Treatment consists of a complex regimen of multiple medications, dietary sodium restriction, increase or maintenance of activity levels, symptom monitoring, and for some patients, fluid restriction. Depending on the physical condition of the patient, partners will have to assist in personal care and in household activities. However, patients with HF probably need predominantly emotional and motivational support in complying with the complex medical regimen and prescribed lifestyle changes [19].

The aim of the study was to develop and test a comprehensive inventory to assess the full range (kind, number and frequency) of performed care giving tasks of partners of HF patients, including emotional and motivational care giving tasks. This article describes the development and first order psychometric testing of a new measure to assess the objective burden in partners of HF patients.

2. Method

The methodological steps employed in this study were to develop the Dutch Objective Burden Inventory (DOBI) and to explore its psychometric properties.

2.1. Development of the inventory

Based on the presumption that the full range of tasks needs to be assessed the inventory should contain different domains of caregiving tasks. The following 6 domains were identified; assistance in physical care and transportation, feeling responsible and being available, assistance in household activities, assistance in financial activities, assistance in disease related activities and emotional or motivational support in following the treatment regimen. To fill these domains items were generated from literature and existing scales [20–22]. Treatment related tasks were derived from the European Guidelines on Heart Failure Management [23], such as supporting the patient in following the prescribed diet or in trying to quit smoking. In total 50 items were formulated; 14 within the domain assistance in physical care and transportation, 3 in feeling responsible and being available, 3 in assistance in household activities, 4 in assistance in financial activities, 13 in assistance in disease related activities and 13 for emotional or motivational support in following the treatment regimen.

For each specific task respondents were asked if and how often they performed this task in the previous 3 months. A 3 point Likert-type response format for the assessment of performed tasks was developed, ranging from never (1) to sometimes (2), to always (3). The final selection of 50 items was presented to a team of specialized heart failure nurses and three partners of HF patients, known at the HF clinic. HF nurses and partners were asked to judge the item selection on its content (are there items missing?, are there items irrelevant?), its feasibility and clarity of questioning. In answer to their reports no items were added or removed, some were rephrased.

2.2. Testing the inventory

To test the 50-item inventory it was administered to a population of partners of HF patients. Data were used for Principal Component Analysis to explore its structure. Furthermore, to evaluate the validity of the inventory and its domains, external variables which are expected to be related to objective caregiver burden were measured. For this purpose the correlations with gender, health status of HF patients and subjective feelings of burden in partners were examined.

Based on literature we expected:

Gender to be related to the number of performed care giving tasks with women performing more care tasks than men [11,24];

Care giving tasks regarding personal care to be associated with the severity of HF and the physical health status of the patient; a worse health status is expected to result in more caregiving tasks regarding personal care [25];

Care giving tasks regarding emotional support to be related with mental health status and depressive symptoms of HF patients; patients with a low mental health status or

symptoms of depression are expected to be in need for more emotional and motivational support [25];

Subjective feelings of caregiver burden to be associated with the amount of care giving tasks performed [13,14].

2.3. Design and sample

Cross-sectional data were gathered from partners of HF patients that participated in the Dutch NHF-COACH trial on the effects of advising and counselling in HF patients [26]. All patients were included during a hospital admission for HF (NYHA II–IV). Patients were at least 18 years of age, with evidence of structural underlying heart disease. There were no specific in or exclusion criteria except for partners to be able to read and understand the Dutch language and to be mentally able to complete a questionnaire. As a rule of thumb a minimum of 5 respondents per item is often used to provide a sufficient sample size for factor analysis [27]. This means that a minimum of 300 respondents is needed to develop the 50-item inventory on objective caregiver burden.

2.4. Procedure

All partners (if available) of the participating patients were approached 1 year after the HF patient was discharged. Partners received the study questionnaire by mail at home and were asked to fill in the questionnaire independently from the patient. Independent datacollectors visited patients and partners at home to collect the questionnaires. Demographic and clinical data of patients were collected by chart review and patient interview. The investigation conforms with the principles outlined in the Declaration of Helsinki.

2.5. Measures

Physical health of the HF patient was assessed by the subscale physical functioning of the RAND 36 questionnaire which is a widely used scale to measure general health [28]. Scores on the physical functioning subscale range from 0 to 100 with 100 indicating optimal physical condition. Severity of HF was defined by the NYHA classification (New York Heart Association). Mental health of the HF patient was assessed by the subscale mental functioning of the RAND 36 questionnaire [28] and by the Centre of Epidemiologic Studies Depression Scale (CES-D) for assessing depressive symptoms [29]. Scores on the mental functioning subscale of the RAND 36 range from 0 to 100 with 100 indicating optimal mental condition. Scores on the CES-D scale range from 0 to 62 with higher scores indicating more depressive symptoms. Feelings of subjective caregiver burden in HF partners were measured by the Caregiver Reaction Assessment scale which has proven to be a valid instrument for assessing caregiver experiences [16]. The CRA consists of 5 independent subscales. For each domain scores range from 1.0 to 5.0, with a higher score representing a higher burden.

2.6. Statistical analysis

First the feasibility of the inventory was assessed by exploring the percentage of missing values per respondent and per item.

After this assessment we conducted a principal component analysis (PCA) in order to explore the structure or underlying dimensions within the data set and to reduce the number of items if possible. The criteria used for a component's extraction were the scree plot, an Eigenvalue above 1.00 and each component had to account for at least 5% of the variance among the items [27]. To improve the interpretation of the component extraction a varimax rotation was applied. Selection of items was based on the following criteria; (a) an item loading exceeding 0.40, (b) second highest loading was at least .20 lower.

For each extracted component a total score was computed by adding the item values in each component and then dividing them by the number of items in that component.

Validity was evaluated by evaluating correlations with the external variables using the Pearson correlations coefficient for the continuous variables and the Spearman's rho correlation coefficient for the ordinal or categorical variables.

Reliability was explored using the Cronbach's alpha as a measure of internal consistency. In general, homogeneity is considered to be sufficient if alpha ranges between 0.70 and 0.90 [27].

3. Results

3.1. Study population

Our study population consisted of 321 partners of HF patients. Partners were predominantly female (75%) and had

Table 1
Study population (*n*=321)

Partners		Mean or % (± SD)
Partner characteristics		
Age	Years	67±12
Gender	Female	75%
Educational level ^a	Low	54%
Patient characteristics		
Age	Years	70±12
Gender	Male	75%
Physical functioning RAND 36		47±29
Mental functioning RAND 36		76±17
NYHA class		
II		53%
III–IV		47%
LVEF (%)		32±14
Number of comorbidities		
None		43%
One		33%
2–5 comorbidities		24%

^a Educational level low = no education/primary school/lower vocational school.

a mean age of 67 years. Patients were slightly older (70 years) and predominantly male. Fifty-seven percent of all HF patients had one or more comorbidities (Table 1).

3.2. Feasibility

The instrument was filled out without main difficulties. Missing values for all separate items on care giving tasks was below 5%. In total 250 (78%) respondents had no missing values, 57 (18%) respondents had only one or two items missing.

Table 2
Rotated component matrix with percentage of explained variance

In the previous 3 months did you support the patient in or by		Component			
		1 ^a	2 ^b	3 ^c	4 ^d
Eating and drinking	1a	.67			
Washing and bathing	4a	.60			
Dressing	5a	.69			
Toileting	6a	.67			
Assisting with appearance	7a	.49			
Mobility at home	8a	.61			
Helping in and out of bed	9a	.80			
Walking stairs	10	.63			
Helping with comfortable position in bed	14a	.72			
Household activities light	15a		.31		.37
Household activities heavy	16a				.44
Shopping	17a				.51
Doing the finances	18a				.70
Filling in forms of reimbursement	19a				.67
Arranging care when necessary 20a					.66
Arranging physical aids	21a				.71
Availability for 24 h	22a	.44			
Caring at night	23a	.50			
Achieving prescription for medication	27a				.54
Achieving medication	28a				.54
Contacting a professional	32a				.42
Following fluid prescriptions	33a		.64		
Following diet prescriptions	34a		.57		
Regular weighing	35a		.55		
Following exercise prescriptions	36a		.49		
Providing comfort	38a			.74	
Talking to reduce anxiety	39a			.76	
Talking to reduce depressive feelings	40a			.78	
Talking to reduce worries	41a			.76	
Showing understanding	42a			.64	
Keeping company	43a			.57	
Motivating to follow diet	44a		.61		
Motivating to quit smoking	45a		.33		
Motivating to be active	46a		.53		
Motivating to take medications	47a		.69		
Motivating to follow fluid prescriptions	48a		.73		
Motivating to start working again	49a		.43		
Participating in conversations with professionals	50a			.36	.35
Percent of variance explained		22.75	7.48	7.12	5.62

^a Personal care.

^b Motivational support.

^c Emotional support.

^d Practical support.

Table 3

Items that were removed from the initial 50-item selection

In the previous 3 months, did you support your partner:
1. In preparing meals
2. In planning and organizing meals
3. With transportation to health care providers
4. With transportation to family and friends
5. In using the telephone
6. In preparing medication
7. In taking the medication
8. In evaluating the need for (extra) diuretics
9. In monitoring symptoms of deterioration
10. In contacting a professional when things get worse
11. In taking care of rest in daily life
12. When I am away, I have to arrange someone else to stay with my partner

3.3. Constructing components

Based on the scree plot, four components could be extracted from the 50-item selection. These four components explained 43% of the total variance. All components had an Eigenvalue above 1.00 (Table 2).

After running several component analyses 15 items did not meet the selection criteria, they were either loading below 0.40 or were loading high on more than one component. Of these, 12 items were removed from the inventory (Table 3). There were three items (15, 45 and 50) that remained in the inventory because their content seemed very relevant. The 38 items that were retained were again analysed and did fit in the four component model.

Following the results of the factor analysis, the original 6 domains with 50 items were reorganized into 4 components consisting of 38 items. The first component which explained most of the variance (22%), consisted of 11 tasks regarding personal care (e.g. assisting in washing, in eating and drinking). The original domain of emotional and motivational support was divided into two relatively independent components. One component was related to motivating the HF patient in following the prescribed treatment regimen (e.g. motivating to follow diet prescriptions). This second component contained 10 tasks and explained 7.5% of the total variance. The third component contained 6 caregiving tasks and referred to emotional support (7% explained variance).

The final component contained 11 practical (household activities) and treatment related tasks (achieving medication). Within this component four of the original six domains (feeling responsible and being available, assistance in

Table 4

Mean scores (SD) for performed care giving tasks and task related burden

Performed care giving tasks ^a	Mean/median (SD)
Personal care	1.16/1.09 (0.3)
Motivational support	1.43/1.30 (0.4)
Emotional support	1.82/1.83 (0.5)
Practical related support	1.97/1.90 (0.5)

^a Range 1–3.

household activities, assistance in financial activities and assistance in disease related activities) are being combined into one component. This final component explained 5.6% of the total variance.

3.4. Validity

Rather independent clusters of performed care giving tasks were measured by the different components as reflected by the component correlation matrix which showed fairly low correlation (ranging from 0.18 to 0.29) between the separate components. Because of this relative independence of the components it was not useful to compute a total score on caregiving tasks performed. Total scores for each component were computed by adding the item values in each component and then dividing them by the number of items in that component. If more than 25% of the items within a component were missing, the case was considered as missing. If less than 25% of the items within a component were missing then the mean score on the other items within that component was imputed. Total scores for all components range from 1 to 3 with a higher score meaning more tasks performed. Mean score for the 4 domains are presented in Table 4.

The correlations with external variables present a preliminary test of the construct validity of the components of caregiving tasks. We found weak correlations between gender and the independent components of caregiving tasks. Female partners tended to perform more motivational care tasks ($r=-0.18$) whereas men tended to perform more personal care tasks ($r=0.13$). As expected, it was found that severity of HF as indicated by the NYHA classification and by the RAND 36 physical functioning is positively associated with the number of performed care giving tasks regarding personal care ($r=0.24$ and $r=-0.43$ respectively).

Table 5
Correlation coefficients between caregiving tasks and external variables

	Personal care	Practical care	Motivational	Emotional
Partner variables				
Gender	.13*	-.07*	-.18**	.01
Caregiver burden				
Disruption daily schedule	.50**	.35**	.37**	.32**
Lack of family support	.17**	.13*	.12*	.01
Financial problems	.18**	.06	.10	.14*
Loss of physical strength	.25**	.07	.19**	.11
Self esteem	.07	.05	.08	.18**
Patient variables				
NYHA class	.24**	.15*	.04	.08
RAND 36 physical functioning	-.43**	-.17**	-.19**	-.29**
RAND 36 mental functioning	-.26**	-.20**	-.13*	-.32**
CES-D Depressive symptoms	.13*	.05	.04	.16**

* $p \leq 0.05$ ** $p \leq 0.01$.

Furthermore, mental health status and depressive symptoms of HF patients correlated fairly high and in the expected direction ($r=-0.32$ and $r=0.16$ respectively) with tasks regarding emotional support. Finally, the components of caregiving tasks were moderately correlated with subjective feelings of burden, especially with the CRA subscale 'disruption of daily schedule' (r ranging from 0.32 to 0.50). (Table 5).

3.5. Reliability

The internal consistency of the components was calculated using the Cronbach's alpha. The components displayed alpha scores from 0.81 to 0.84.

4. Discussion

In this article the development and initial validation of a new measure on objective burden in partners of HF patients was described. The final inventory is presented as a promising self-report instrument to assess the objective demands on partners of HF patients.

A 50-item inventory was developed on the basis of literature, expert opinion, and existing scales. Exploratory component analysis deduced 38 independent care giving tasks out of the initially 50 care giving tasks that were assessed. Component analysis indicated that four meaningful, independent clusters of care giving tasks could be identified. From the original six, four domains (feeling responsible and being available, assistance in household activities, assistance in financial activities and assistance in disease related activities) were combined into one which was labelled as practical and treatment related caregiving tasks. Two other domains; emotional and motivational support, were divided into two separate and relatively independent components. The fourth domain was labelled as tasks regarding personal care. The components proved to be internally consistent, uni-dimensional and evidence for sufficient reliability was found.

The Dutch Objective Burden Inventory (DOBI) is a new and unique instrument because it focuses purely on objective caregiver burden and it provides information on the full range of caregiving tasks that partners perform. The DOBI can differentiate into four specific kinds of care giving tasks that are performed, it contains not only tasks regarding practical care and personal care but also tasks related to emotional and motivational support. Our hypothesis that HF patients probably need predominantly emotional and motivational support was confirmed by our data which showed that the amount of performed tasks regarding personal care was limited and that most care giving tasks that were performed were related to emotional and practical support.

In our opinion it is possible to expand the DOBI with a dimension of subjective, task related feelings of burden. This task related burden would provide information on the specific difficulty of certain tasks and therefore this concept could lead us to concrete directions for supportive interventions.

For each item, relating to a specific task, a question on the perceived amount of burden, can be formulated.

The associations that were found with related constructs provided preliminary evidence for the validity of the subscales. A worse health status of the HF patient seemed to increase the amount of care giving demands regarding personal care. The same relationship was found between mental health of the patient and increased amounts of emotional support.

As Karmilovich [11] found significant differences in the number of performed care giving tasks between male and female partners, our result show that this may be true for certain kinds of care giving tasks. Although correlations were weak, female partners tended to perform more motivational care giving tasks and male partners tended to perform more care giving tasks regarding personal care.

Our data also confirmed earlier findings [13] that objective burden and subjective burden seem to be partly different concepts. The amount of care giving tasks performed was associated with subjective feelings of burden measured by the Caregiver Reaction Assessment scale, but only to some extent meaning that subjective burden can only partly be explained by the kind and number of care giving tasks. In future research it is important to investigate which factors mediate the relationship between objective burden and subjective feelings of burden. The DOBI, as an instrument that focuses explicitly on objective burden makes it possible to clearly distinguish both concepts and therefore can be very helpful in such kind of future research.

Although the DOBI appears to be a promising instrument to assess objective burden, there are points for improvement and further testing is needed.

The inventory is developed to assess the objective burden of partners of HF patients and contains items that are specifically applicable to these partners. However, many of the tasks that are assessed will also be applicable to partners of patients with other chronic diseases. It may be worthwhile to investigate the usefulness of the DOBI in other partner-populations.

A confirmatory factor analysis on an independent sample of HF partners is needed to confirm the existence and reliability of the components. Furthermore, our study population was predominantly female (75%) and therefore the number of male partners was too small to test for gender independence. However, the composition of the components may be different for male and female partners. Finally, our study population consisted of HF partners that were caring for a HF patient for at least 1 year. The inventory was completed at home with the patient in a relatively stable condition. It would be of importance to test the inventory in different situations to explore its sensitivity to events and different stages of the disease.

Acknowledgments

The NHS-COACH study was granted by the Netherlands Heart Foundation (Grant 2000Z003). Prof. dr. van Veldhuisen is an established investigator of the Netherlands Heart Foundation (Grant D97.017).

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